

NPM #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)

Impact on National Outcome Measures: Overall, the SLAITS survey found 66.49% of families are satisfied with the services they receive and feel they are partners in decision making. This is higher than the overall national result of 57.53% of families who report satisfaction with the services they receive and feel they are partners in decision making.

a) Report of 2003 Major Activities

1. Information and Referral Services Satisfaction Survey—Direct Health Care Services—CSHCN

Although the CSHCN Program does not provide direct health care services to children with special health care needs or their families, the CSHCN Program is committed to assuring families are satisfied with the services received from the Regional CSHCN Centers and LPHDs.

An Information and Referral Services Satisfaction Survey was sent to over 1,100 families of children with special health care needs who utilized information and referral services from the Regional CSHCN Centers or LPHDs during 2003. The results revealed an average satisfaction score of 4.662 on a 5.0 scale.

2. Financial support to County Parent Liaisons—Infrastructure Building Services—CSHCN

The CSHCN Program requires the five Regional CSHCN Centers to identify a CPL through partnering with the LPHD. Financial support is offered to CPLs to increase participation in activities that positively impact policies, programs and services attend educational workshops or participate in family centered activities in their communities.

3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN

Parents play a central role in many aspects of the CSHCN Program. Parent involvement is supported through the continued employment of a Parent Consultant at the CSHCN Program. Parent Coordinators are employed at all five Regional CSHCN Centers. Parents are employed at the Wisconsin First Step Hotline to provide information and referral services.

4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN

The role of families has been strengthened as they continue to participate on the NBS Advisory Committee, Birth Defects Council, Universal Newborn Hearing Screening Workgroup, and MCH Advisory Committee.

5. Parent input into the MCH Block Grant Application—Infrastructure Building Services—CSHCN

In 2003, parent input into the MCH Block Grant Application was requested from over 500 parents in attendance at the annual Circles of Life – Families Conference. A Workbook for Families regarding the MCH Block Grant was adapted and developed from a Family Voices publication and distributed with the public input invitation in order to solicit comments from family members.

b) Current 2004 Activities

1. Information and Referral Satisfaction Survey—Direct Health Care Services—CSHCN

The information and referral satisfaction survey is an ongoing survey that will continue throughout 2004 in order to assure the services, provided through the CSHCN Program, are meeting the needs of the families. A "2003 Annual Program Evaluation Report" is being developed and will be widely distributed during the last six months of 2004. The report provides a satisfaction summary with the information and referral services received from the CSHCN Program.

2. Financial support to County Parent Liaisons—Infrastructure Building Services—CSHCN

Financial support is being provided to over 70 CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN

The CSHCN Program has integrated the Parent Consultant role in several staff positions. More emphasis will be placed to promote parent involvement in the Medical Home Initiative to assure a family centered perspective is maintained and parent partners are supported throughout the process.

In addition, each of the five Regional CSHCN Centers employs a parent coordinator. The Wisconsin First Step Hotline employs parents with children with special health care needs to provide information and referral. There is continuing support for a CPL in each of Wisconsin's 72 counties.

4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN

We are increasing the number of parents providing input into the 2004 MCH Block Grant Application by requesting input from over 500 parents who attended the annual families conference called Circles of Life. Additionally, methods of gathering parent input are being discussed as we begin planning the process beginning this fall.

5. Parent input into the MCH Block Grant Application—Infrastructure Building Services—CSHCN

Parents are an important partner as we work with nine practice teams to develop Medical Homes in Wisconsin.

6. Collaboration on the implementation of a Family to Family Health Information Center grant with Family Voices

In 2004, Family Voices receive a CMS grant to develop the above named Center. The CSHCN Program has been actively involved in the planning and implementation of activities related to this grant including the development of fact sheets for families, providing training to families regarding health benefits and coordinating information and assistance services across the state so that families can access information easier.

c) 2005 Plan/Application

1. Information and Referral Satisfaction Survey—Direct Health Care Services—CSHCN

The CSHCN Program will continue to assure families are satisfied with those services received from the Regional CSHCN Centers including information and referral, parent to parent support and service coordination.

2. Financial support to County Parent Liaisons—Population-Based Services—CSHCN

Financial support will continue to be provided to CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN

The continued employment of parent consultants at all five Regional CSHCN Centers, parent consultants at the First Step Hotline, and the support of a CPL in each of the counties will continue throughout 2005. The Medical Home Initiative will assure a family centered perspective.

4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN

Parent input will be gathered through the Needs Assessment process throughout the beginning of 2005 and will be summarized and used to develop future planning for the next five year cycle.

5. Participation of families as active partners in the Wisconsin Medical Home Initiative—CSHCN

Parents will continue as an important partner as we continue to develop Medical Homes within Wisconsin. Information gathered from parents throughout 2004 will be used to develop the role parents will have in 2005.

6. Collaboration on the implementation of a Family to Family Health Information Center grant with Family Voices

In 2005, the CSHCN Program will continue to be actively involved in the implementation of activities related to this grant including the development of a training and lead trainers regarding health benefits.